



What We Talk About When We Talk Is it Time for a New Paradigm? About Self-Neglect*

*Apologies to Raymond Carver

LEARNING OBJECTIVES

- Be Familiar with the Definition of Self-Neglect
- Understand the Relationship of Self-Neglect to Other Types of Elder Abuse
- Ask Some Questions About How We Think About Self-Neglect

Conflicts of Interest

- None

Elder Justice Act

Self-neglect.—The term “self-neglect” means an adult’s inability, due to physical or mental impairment or diminished capacity, to perform essential self-care tasks including—

- obtaining essential food, clothing, shelter, and medical care
- obtaining goods and services necessary to maintain physical health, mental health, or general safety; or
- managing one’s own financial affairs.

What is Self-Neglect?

- Lack of self-care to an extent that it threatens personal health and safety
- Neglecting to care for one's personal hygiene, health or surroundings
- Inability to avoid harm as a result of self-neglect
- Failure to seek help or access services to meet health and social care needs
- Inability or unwillingness to manage one's personal affairs

The inability (intentional or non intentional) to maintain *socially and culturally* accepted standards of self-care with the potential for serious consequences to the health and well being of the self-neglecters and perhaps even to their community

Gibbons, Lauder and Ludwick (2006)

Adult Maltreatment Report | 2021

Exhibit A: 2021 Data at a Glance

Submitted by	Allegation type*
59.2% professionals	50.0% self-neglect
15.8% relatives	24.2% neglect
4.7% self-reports	24.2% exploitation
12.8% other^	12.7% physical abuse
	1.5% sexual abuse

268,902 (34.2%)
Individuals had a substantiated investigation (victims)

46.4% of clients and 52.8% of victims
Received APS services



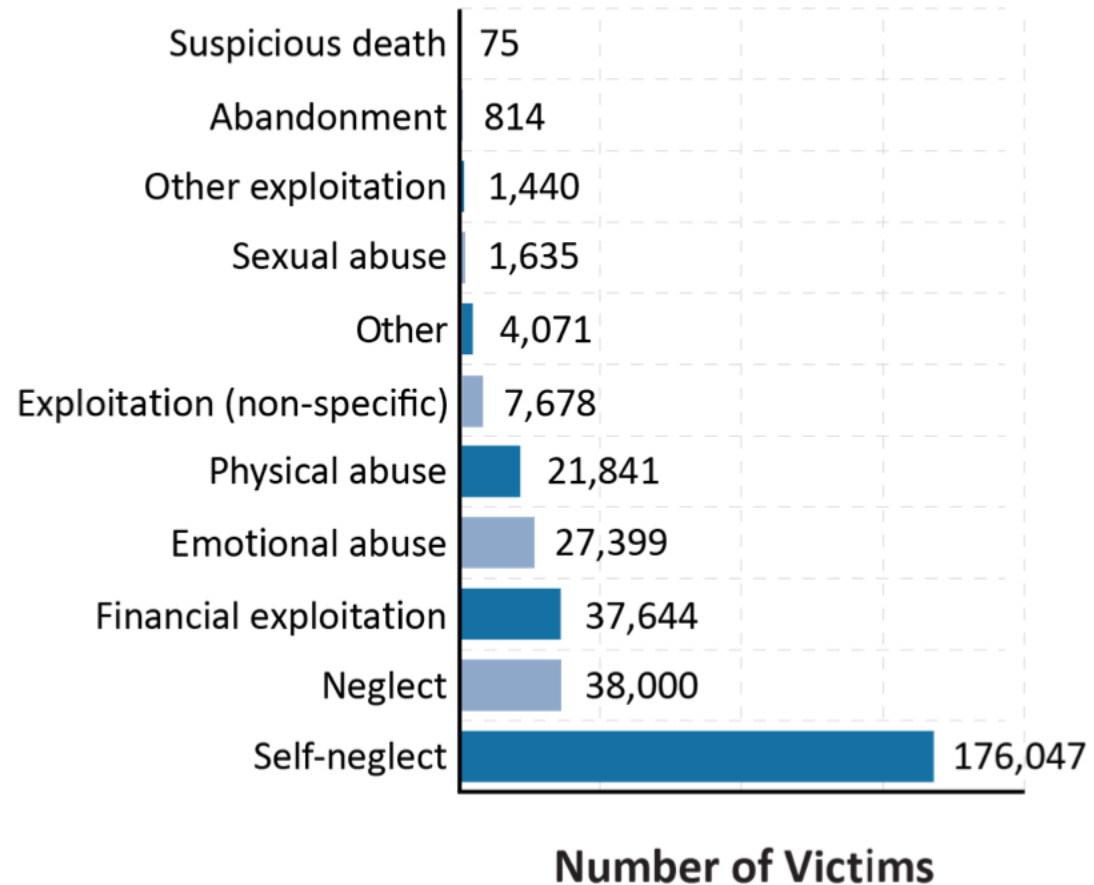
2021 Data at a Glance

^ Other report source includes: in-home caregiver, substitute decision-maker, and other nonprofessional.

* A single investigation may have more than one maltreatment type.

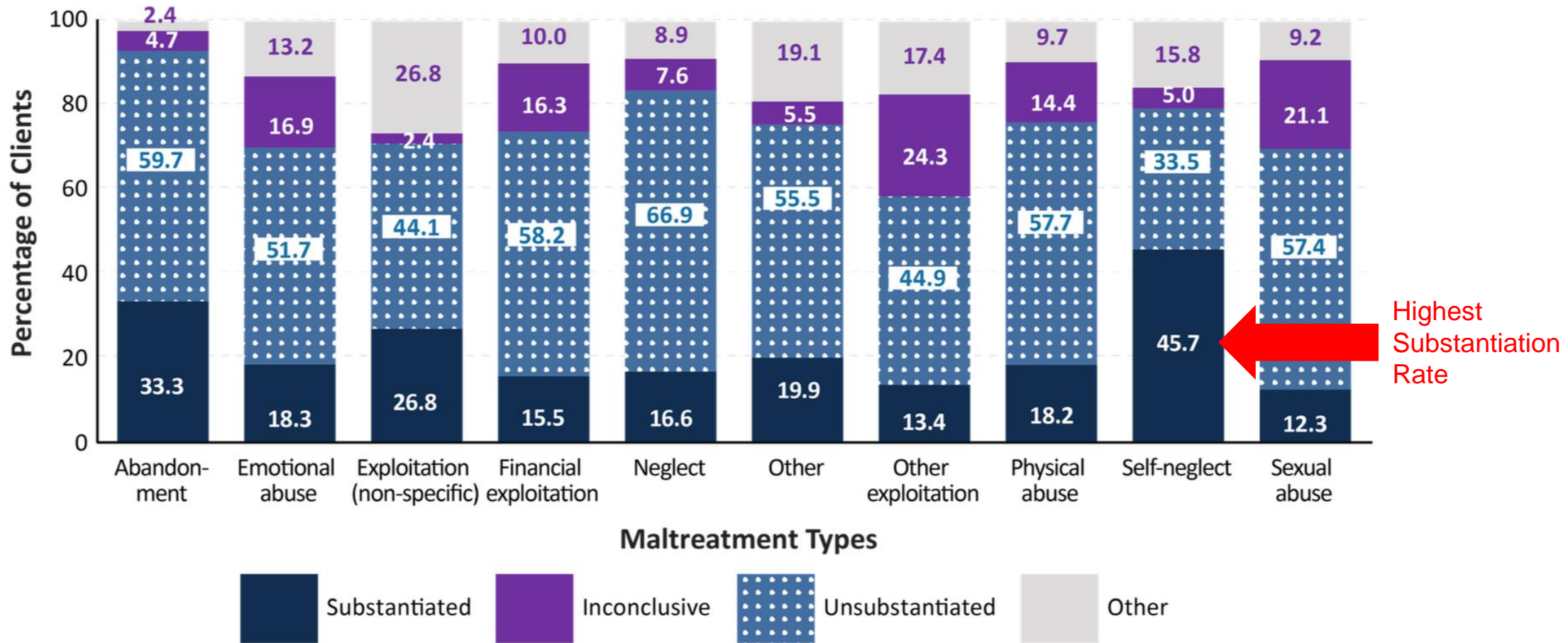
Adult Maltreatment Report | 2021

Exhibit 2.6: Victims by Maltreatment Type
Maltreatment Type



Adult Maltreatment Report | 2021

Exhibit 2.7: Allegations by Disposition and Maltreatment Type



Note: Based on data from 36 states for 628,976 allegations.

Common Characteristics of People Who Neglect Themselves

- Women (possibility because more women than men live alone)
- Depressed and/or increasingly confused
- Frail and older
- Have alcohol and drug problems
- Have a history of poor personal hygiene or living conditions

Medical Consequences of Self-Neglect

- 2.5 x Rate of Emergency Department Usage
- 5 x Rate of Nursing Home Placement if Substantiated by APS
- Almost 6 x Rate of Death Within 1 Year of APS Substantiated Self-Neglect
- Higher Rates of Hospitalizations and Re-Hospitalizations
- Source of Distress for providers/APS Caseworkers – steadfast refusal of care

Narratives of Self-Neglect in Cognitively Intact Older Adults

Experience	n (%)
Victim of psychologically traumatic loss, separation, or abandonment	20 (29)
Victim of violence, physical trauma, or sexual abuse	13 (19)
Exposure to war or political violence	6 (9)
Prolonged mourning	5 (7)

Behavior Pattern	n (%)
Significant financial instability	16 (23)
Severe lifelong mental illness	11 (16)
Mistrust of people or paranoia	9 (13)
Distrust and avoidance of the medical establishment	9 (13)
Substance abuse or dependence	9 (13)

Some Themes

- Most do not see themselves as ‘self-neglecting’ at all
- Many describe their home as their “palace”
- Want to maintain self-control and self-sufficiency
- Often services offered don’t respect their lifestyles or preferences
- Social systems have generally failed them in their past (systems neglect)
- Highly positive self-appraisals
- Strong spirituality and belief in God
- Deep connection with their pets
- Feelings of despondency and experienced suffering, losses, and up-rootedness throughout their lives

Hypotheses

<p>Depression</p> <p>Diminished Social Networks</p> <p>Poor Physical Health</p> <p>Poor Mental Health</p> <p>Impaired Physical Functioning</p> <p>Economic Dislocation</p> <p>Lack of Access to Social or Health Services</p> <p>Impaired Cognitive Functioning</p> <p>Pain</p> <p>Geriatric Syndrome*</p>	<p>Functional Impairment</p> <p>Nutritional and Vitamin Deficiency</p> <p>Alcohol or Substance Use Disorders</p> <p>Vitamin E Levels</p> <p>Homocysteine</p> <p>Frontal Lobe Dysfunction</p> <p>Oxidative Stress</p> <p>Personality Traits</p> <p>Traumatic Histories</p> <p>High Perceived Self-Efficacy Scores</p>
--	--

Predominant characterization of self-neglect is one of

* multifactorial health conditions that occur when the accumulated effects of impairments in multiple systems render [an older] person vulnerable to situational challenges

Deficits, Disease, and Disorders

Older self-neglecters desire to be treated with normalcy and are actively interacting with their environment and reacting to threats to their identity

Yu M, Wang W, Gu L, Ramachandran HJ. Perspectives and experiences of living with self-neglect among older adults: A systematic review and meta-synthesis. *J Nurs Scholarsh*. 2023 Jul;55(4):771-781. doi: 10.1111/jnu.12854. Epub 2022 Dec 9. PMID: 36494758.

Self-neglect needs to be seen within the context of personal and environmental living circumstances, culture, beliefs, family relationships, and health needs

What We “See”	What The Person “Sees”
Squalor	A Palace
Hoarding	Treasured Possessions
Isolation	Self-Sufficiency
Unattended Medical Problems	Distrust of Doctors and Health Systems
Family	Betrayal

Knowing – understand the person

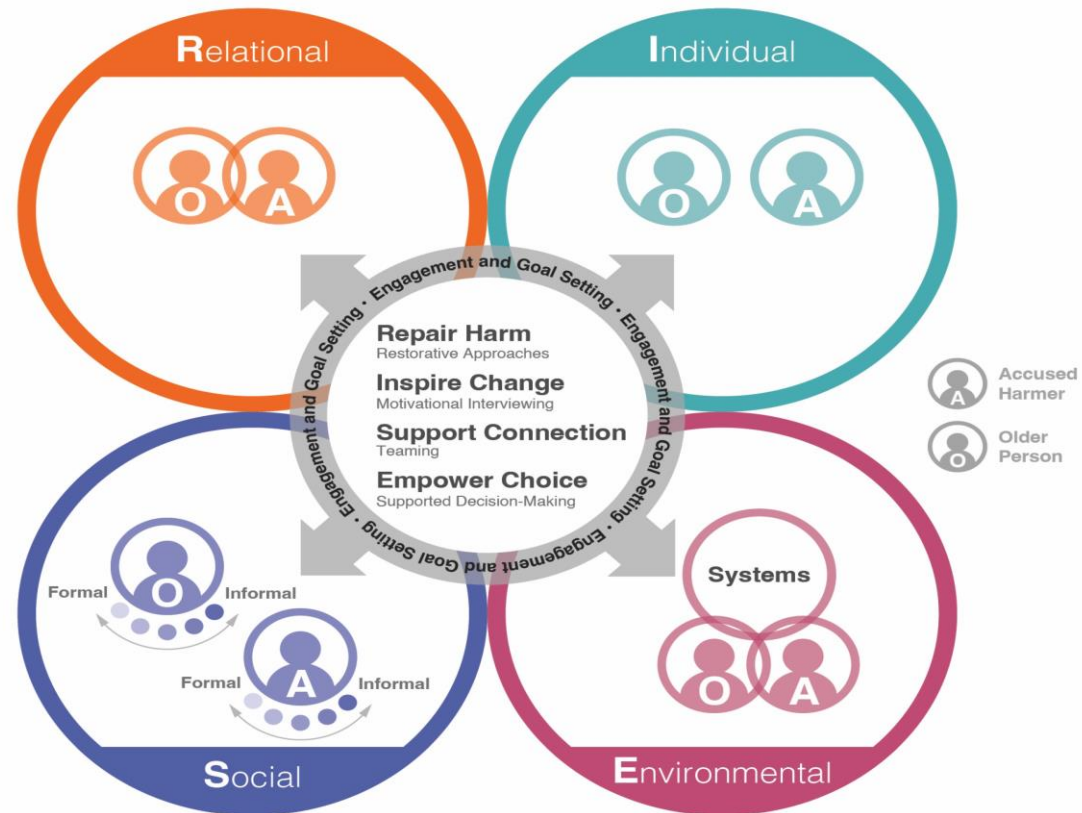
Being – respect, empathy, honesty, reliability, care, keeping company

Doing – start small, decide with others when intervention is required

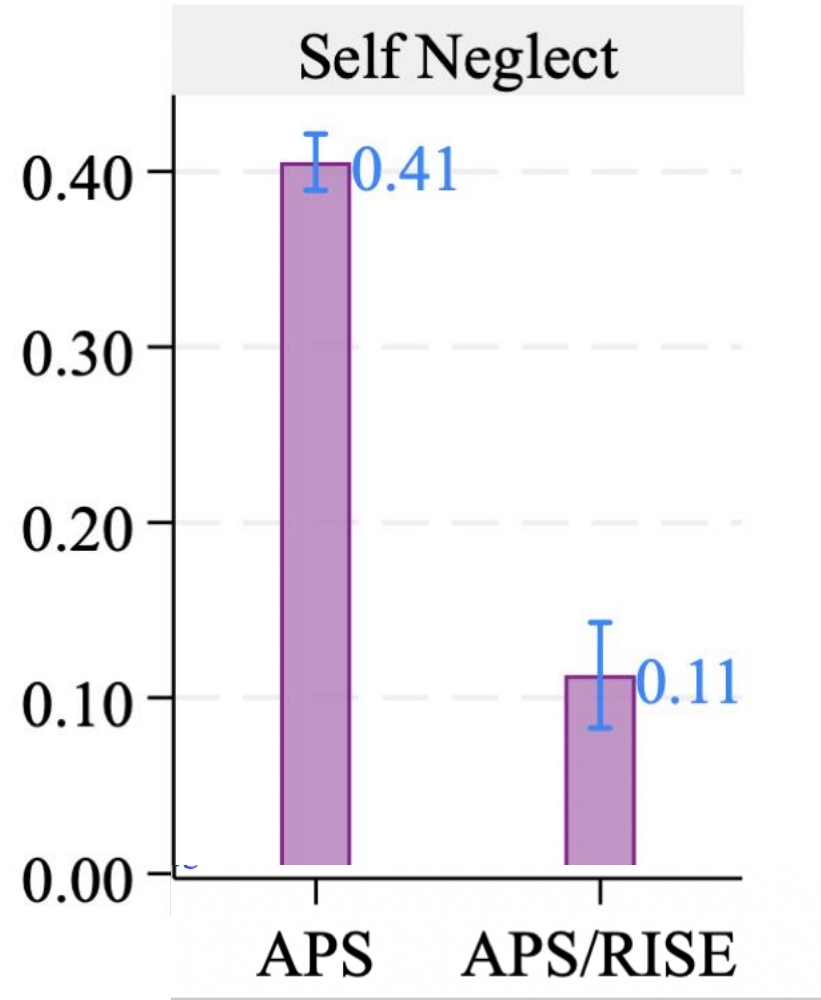
RISE

Repair Harm **I**nspire Change **S**upport Connection **E**mpower Choice

A Conceptual Model of Integrated and Restorative Elder Abuse Intervention



Impact of RISE on Probability of Repeat Investigations by APS



Safeguarding and Duty to Care

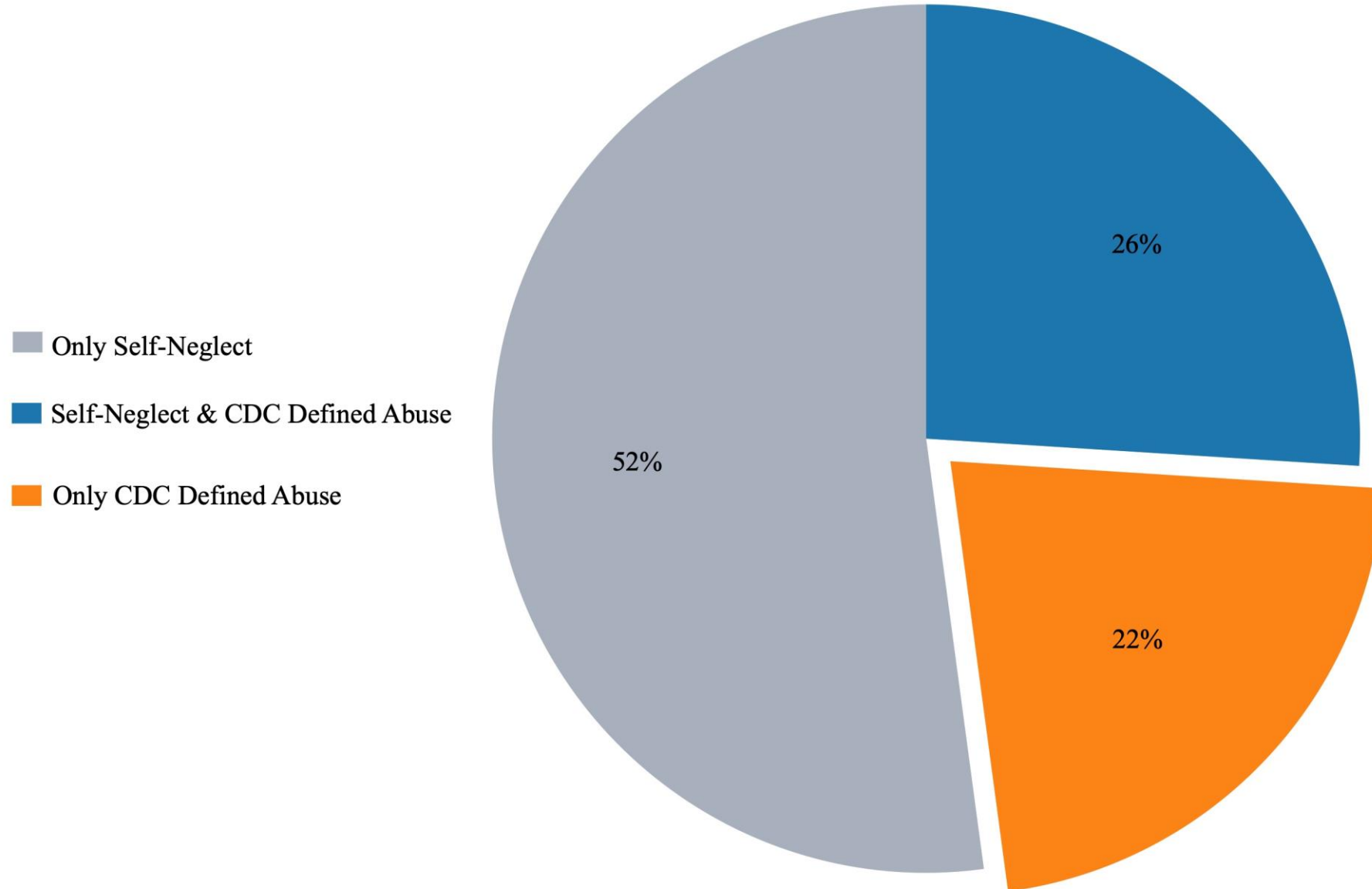
- Persons who resist medical/social interventions are often troubling to caring professionals because they challenge our ability to meet one of our fundamental goals: to act for the good of the person
- Make it Strength Based
- Capacity or not, our goal is to help that person start to CARE and not focus on the NEGLECT
- It is probably the only way to keep them safe AND respect their choices

Some Questions

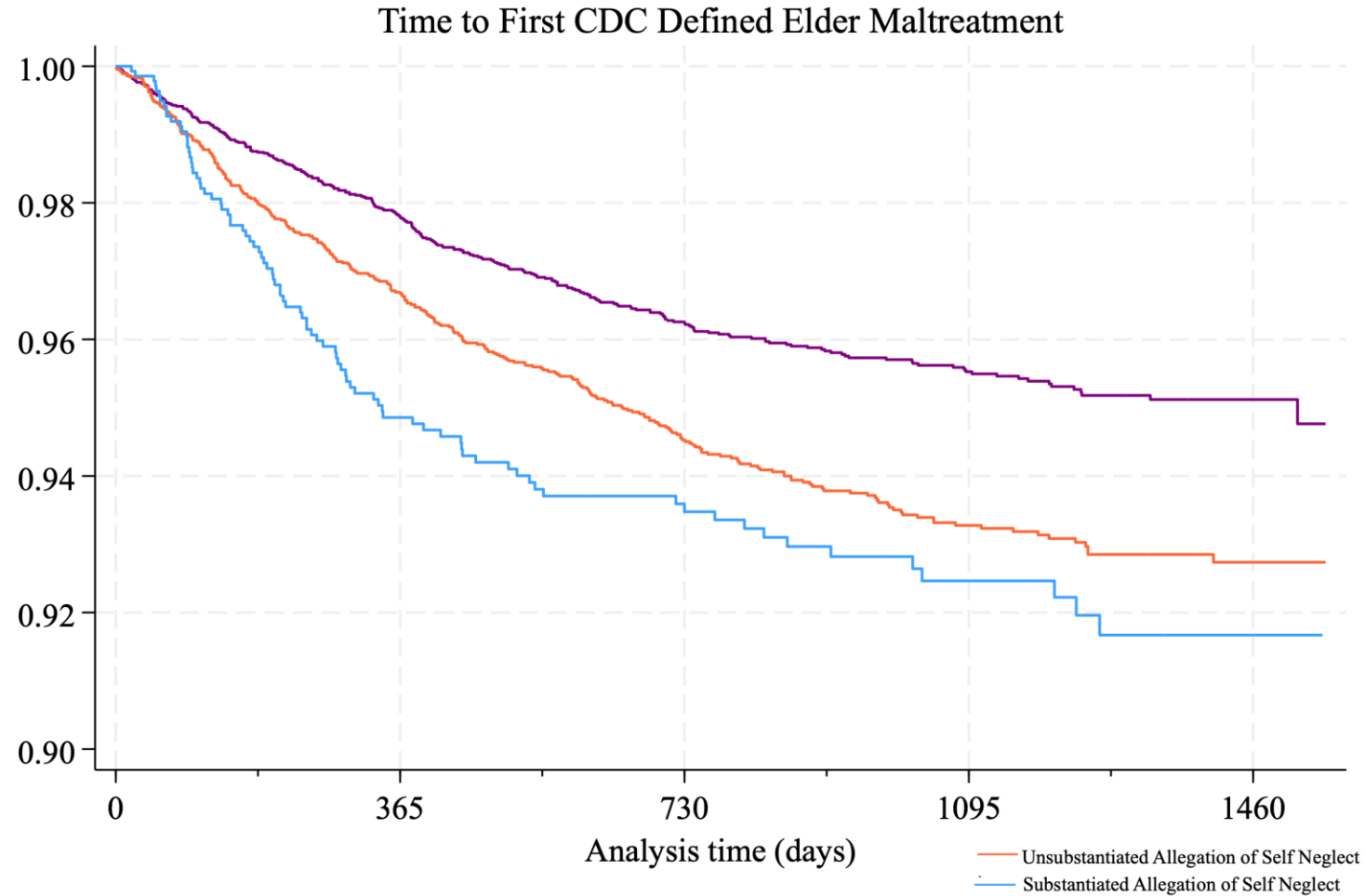
If Self-Neglect is by far the most common form of adult maltreatment ...

- Why does the CDC not measure it?
- Why is it not discussed when we discuss prevalence of adult maltreatment? (1 in 10)
- Why are there very few grants available to specifically study this?
- Why are there no ICD10 Codes for Self-Neglect (multiple ones exist for other forms of suspected or confirmed Adult Maltreatment)?
- Why do we see this differently?

Maine APS Data: First Substantiated Allegation by Type (2017-2021)



CDC Defined Abuse after Substantiated or Un-Substantiated Self-Neglect



First allegation self-neglect (substantiated)

	CDC defined abuse	Caregiver neglect	Emotional abuse	Financial abuse	Physical abuse
Median time to next substantiated abuse (days)	215 days	220 days	307 days	245 days	388 days
Incident rate ratio (CI)	1.49 (1.18–1.86)	1.71 (1.31–2.21)	1.26 (0.80–1.90)	1.41 (1.02–1.92)	2.23 (1.41–3.44)
Attributable risk proportion % (CI)	33 (15–46)	42 (24–55)	21 (–24–47)	29 (2–48)	55 (29–71)

What is all this telling us?

- Self-Neglect is NOT easily separable from other forms of Adult Maltreatment
- Self-Neglect MAY account for up to 1/3 of all future cases of CDC Defined Abuse
- Self-Neglect does NOT easily fall into ANY clear diagnostic category
- Self-Neglect does NOT have an easily identifiable cause
- Self-Neglect has a tone of BLAME

Is it Time to Reconsider What We Mean by Self-Neglect?

What is a Syndrome?

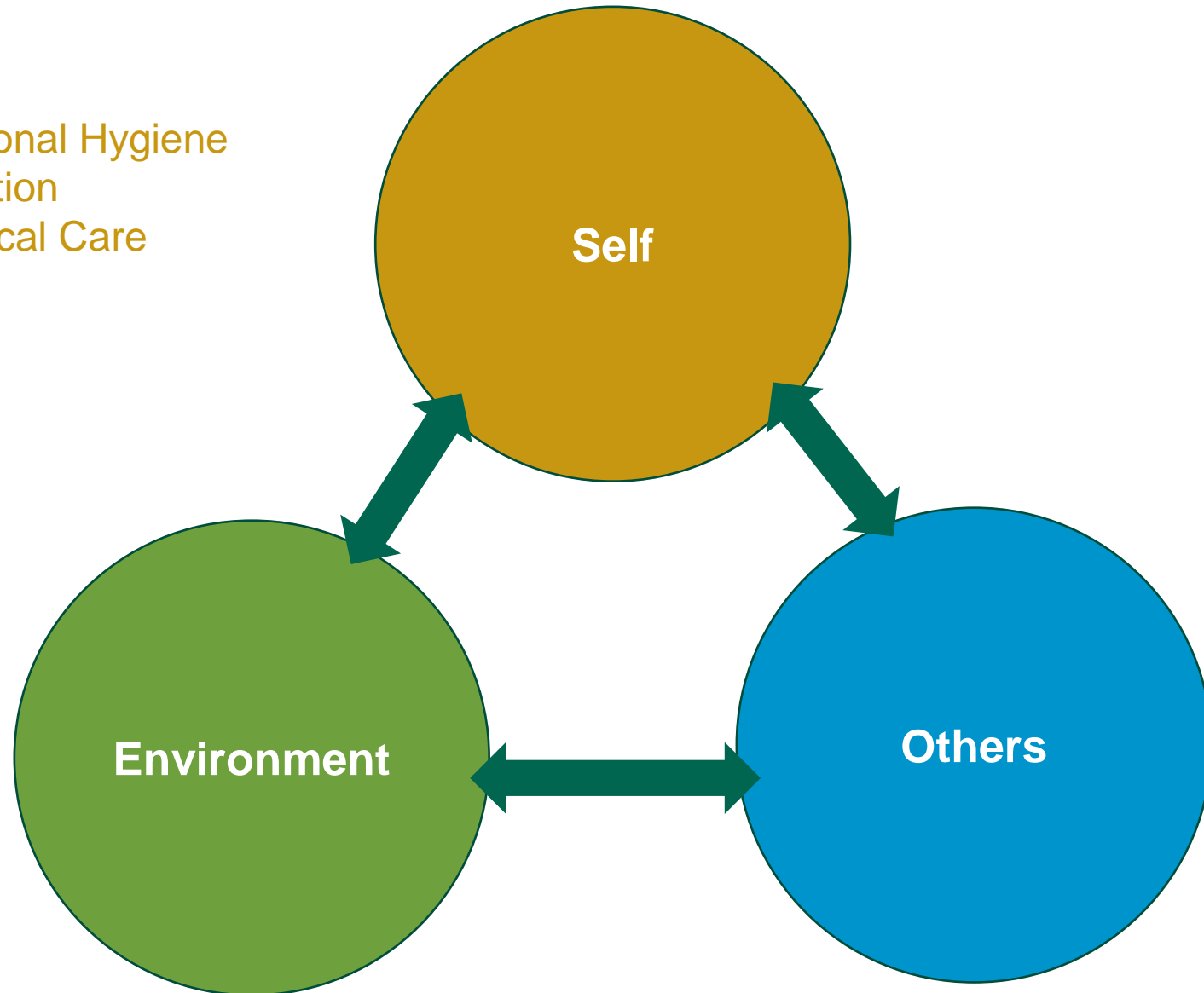
From the Greek word meaning 'run together'

A syndrome is a recognizable collection of symptoms or conditions that occur together for which a direct cause is not necessarily understood

Common examples:

- Chronic Fatigue Syndrome
- Post-COVID Syndrome
- Irritable Bowel Syndrome
- Sudden Infant Death Syndrome

- Personal Hygiene
- Nutrition
- Medical Care



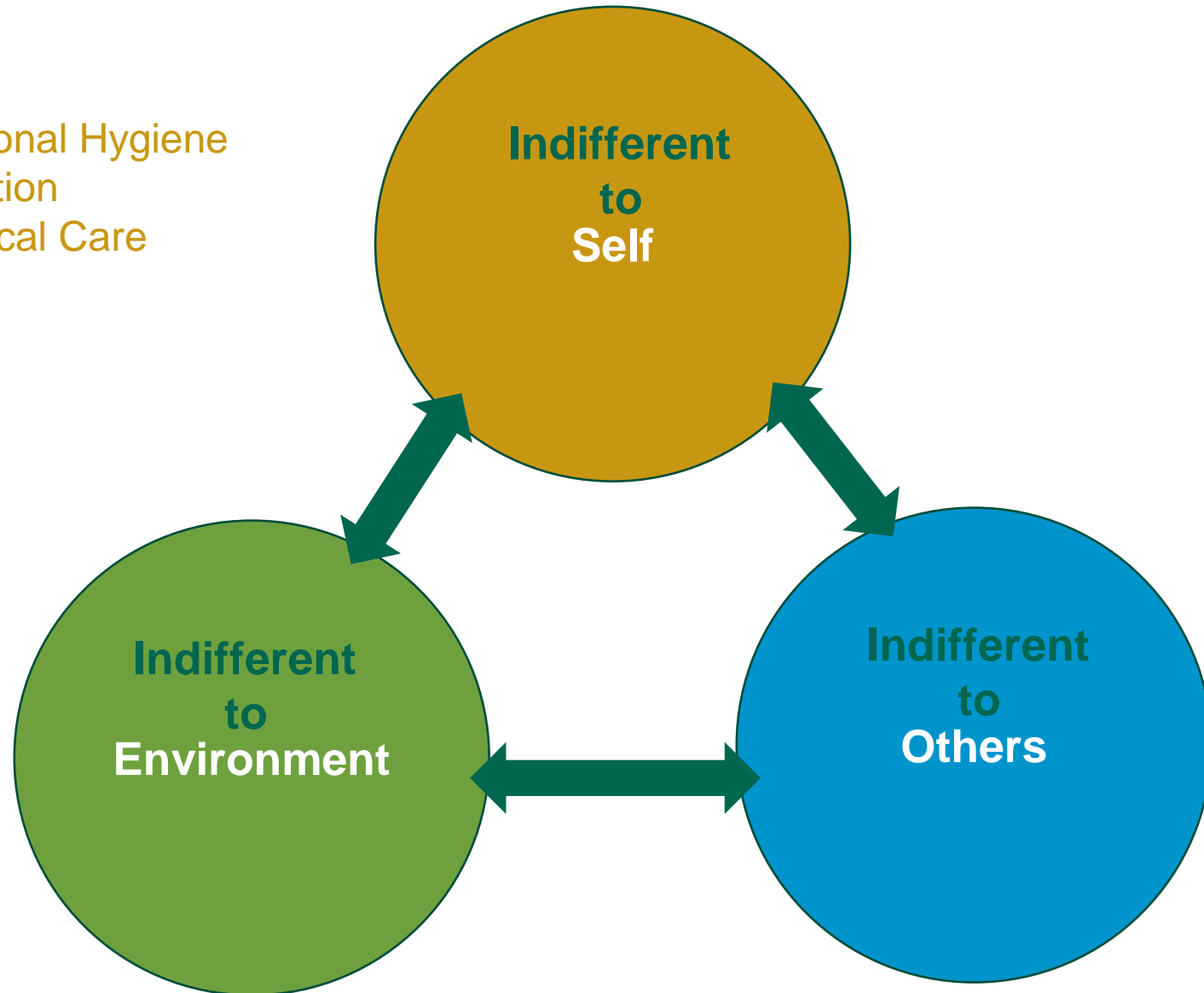
- Hoarding
- Squalor
- Dangerous Homes
- Animals/Pets

- Limited Social Networks
- Often Estranged

Syndrome of Self-Neglect

Insignificant to the patient is the need to care for or attend to something; detached

- Personal Hygiene
- Nutrition
- Medical Care



- Hoarding
- Squalor
- Dangerous Homes
- Animals/Pets

- Limited Social Networks
- Often Estranged

Please Remember...

- Half of all APS cases in Maine are **Syndromic Indifference**
- 25% of all APS cases in Maine are both **Syndromic Indifference** and other forms of Elder Abuse
- **Syndromic Indifference** is a cause of other forms of Elder Abuse in 33% of all cases
- RISE is associated with a 4x reduction in repeat APS Investigations in persons with **Syndromic Indifference**